

**Senate Special Committee on Aging**

**Roundtable Discussion**

***Continuing the Conversation:***

***The Role of Health Care Providers in Advance Care Planning***

**STATEMENT OF**

**Samira Beckwith**

**President and CEO of Hope Healthcare Services**

**Chairman Nelson, Ranking Member Collins, and other distinguished Committee Members:**

Thank you for the invitation to be with you today. My name is Samira Kanaan Beckwith and I am President and CEO of Hope HealthCare Services serving Southwest Florida.

It is truly an honor to participate in this Roundtable discussion on these critically important issues. My interest in care for people with serious illness began nearly 40 years ago when I was diagnosed with Hodgkin's disease while a graduate student in the College of Social Work at The Ohio State University. During this experience, I saw the need for systematic changes in how care is provided for people with serious and advanced illness. It was also during this time that many others throughout the U.S recognized the need to alleviate the suffering and provide expert comfort care for people at the end of life. This group of Hospice Pioneers worked with Congress to establish the Medicare Hospice Benefit in 1982.

Since then, hospice care has been provided to millions of people and yet is still one of the best kept secrets. The comment we most often hear from patients and families is "I wish someone would have referred us to hospice earlier." Most people still find talking about end of life care to be a difficult topic and avoid it for as long as possible. As a result, there are many myths and misunderstandings about hospice and a major reason that today's panel discussion is so very important.

Hospice is person-centered care provided by a team of staff and volunteers. This specialized care for people facing a life threatening illness or injury provides the best care possible during a most difficult time for both the patient and the family members.

Hope Hospice was established in 1983 and now serves nearly 6,000 people each year. After seeing so many unmet needs for people with advanced illness, we established Hope HealthCare Services as a Community Centered Comprehensive Care System to

meet the needs of people not eligible for hospice. The programs added include the Program of All-Inclusive Care for the Elderly (PACE) program, a community palliative care program, a children's hospice program, a Medicaid pediatric program for children who are not expected to live to be over 18, a Parkinson support program, Adult Day Centers, Community Care for the Elderly (CCE), specialized caregiver classes and grief programs. Together, Hope serves 8,000 patients annually through the work of 1,000 employees and 1,200 volunteers with an annual operating budget of over \$100 million.

Hope HealthCare Services is also a founding member of The National Hospice Work Group and The Hospice Innovations Group, two collaborative groups of community-based hospices with a focus on operational innovations and emerging care delivery models for advanced illness. One of our goals is to strengthen the current hospice benefit to preserve the true core of hospice while actively participating in building a more compassionate, efficient and responsive health care system for Americans. We share the goals of many of the stakeholders in the advanced illness community in strengthening the care continuum and reinforcing the care bridge for the seriously ill into hospice, a benefit that, is serving dying Americans very well.

Additionally, I serve on the Board of Directors of both the National Hospice and Palliative Care Organization and the National PACE Association.

As has been well documented, there are an increasing number of people living with serious and advanced illness, including many more people with illnesses that involve decline in cognitive and functional status. Our health care system is excellent at managing acute episodic illness or injury but there is great need to establish appropriate care systems for the number of aging Boomers with advanced progressing illness.

There are many obstacles facing hospices in being able to provide these much needed services. Hospice benefits need to be more accessible for individuals as they experience significant physical, emotional, spiritual, and financial burdens and become eligible for hospice care.

Hospice care is under-utilized and yet illustrates the key features sought in many of the CMS Innovation Initiatives. The foundational elements necessary to build what many refer to as advanced illness coordinated care or transition programs are the underlying concepts of hospice care. In reality, hospice serves as an innovation ahead of its time. The notion of highly coordinated care across settings with interdisciplinary teams of clinicians, social workers, and spiritual advisors all working toward personal and health care goals developed in consultation with patients and their loved ones is a concept being sought and tested for our health care system is the hospice benefit. Hope, as a community organization, has been providing this care for 30 years, and we know what it takes to make this model work.

Significant obstacles to being able to provide care include the amount of administrative and regulatory burden that is taking the time away from patient care and not adding any value. Examples include the new Part D requirements for hospice and the face to face

requirement. The effort to want to standardize requirements across providers and patient populations utilizing a “one size fits all” approach does not work for end-of-life care. The Medicare Hospice Benefit was designed to be flexible enough to meet the wide variety of needs and experiences that can be present in our vulnerable patient population. These are the very aspects of the benefit that seem threatened now through the scrutiny on variations in length of stay, levels of care, setting of care and utilization of various staff on the hospice interdisciplinary team.

In fact, there have been nine significant regulatory changes in 2014 without coordination on implementation in and among the policy changes and without consideration of impact on patients and families. A thorough examination of these is critically needed by a committee such as this.

We must develop systems of care that properly integrates care services across the spectrum and properly identify which patients would benefit most from interventions. Addressing the entire continuum requires us to address the quality of care for those in the “pre-hospice” portion of the health care continuum living with advanced illness and allow a smooth transition to hospice care. Concurrent care options would allow this transition. Each person with serious illness is different in terms of their social, medical and emotional needs, and functional status. The skills, expertise, and experience of hospice professionals and the interdisciplinary coordinated care model of hospice are well-adapted for this range of circumstances.

There are additional challenges that need to be addressed in order to meet the demands of older Americans, some specific to the Medicare Hospice Benefit and others that are pertinent to the entire health care community. For instance, patients who elect hospice must often relinquish concurrent, potentially life-prolonging therapies that can lead to forced choices or late admissions into hospice. Many will only choose hospice after exhausting all other options, often doing more harm than good when a higher quality and longer, prolonged life could have been pursued in hospice at lower costs. Allowing concurrent care enables a person to move through the continuum care in a less threatening environment and has been proven through numerous studies.

Another key challenge is eligibility. A Medicare patient must have a prognosis of six months or less if the disease takes its normal course. Due to recent medical, financial, and social advances in the past few decades, life expectancy is not readily predictable for a person diagnosed with the common life-limiting serious conditions such as cancer, heart failure or Alzheimer’s disease. With the same diagnosis, one person may live to five months while another may live years. We are often forced to discharge patients because they are not showing evidence of decline and yet their prognosis is still under six months. Many of these people then wither away for the next few months without care until they again decline enough to come on back on Hospice Services. I would ask each you to reach out to the hospices in your community and make a home visit to see this for yourself.

Next, hospice services are often under-recognized and under-utilized. As noted before, Hospice mirrors many key features that have been promoted in national health reform – their services are bundled and seek to provide comprehensive, person-centered quality care. Unfortunately, many still hold serious misconceptions regarding hospice care. The focus is on maximizing life – not settling in a place to die.

This notion is the result of a deep misunderstanding and can only be mitigated by cultural change. It is crucial to educate patients, families, and caregivers across the care continuum to ensure that hospice is integrated into care models to provide the most benefit to patients. We must examine new methods of communication and the language used to reflect modern economic, social, and political realities. This will help to increase access and length of stay for hospice patients that will improve quality and satisfaction for those when they need it most.

There is disagreement over when patients should be admitted into hospice. Some acknowledge that the vast majority of people are accessing hospice services too late. Nationally, hospice is a six month benefit with a median length of stay of around 20 days and with 35% of patients living only seven days or less. On the other hand, there is another cohort of hospice patients that live beyond 180 days – 12% of total patients. While intended to reduce fraud and abuse, the highly punitive payment oversight process of hospice targeting those 12% of users has back-fired, leading to more costly and poorer quality of care. This can be partially rectified by easing the administrative burden on hospice providers. In addition, regulatory and payment mechanisms must be assessed in a comprehensive way, looking at the entire continuum for patients with advanced illness rather than by just benefit by benefit.

We must re-invest in hospice care and recognize it as an integral component of the care continuum for those with chronic or advanced illness. The health and well-being of Americans who will soon suffer from advanced illness will depend on providing seamless transitions from inpatient settings to the home or hospice. Only then will we be able to achieve the peace, honor, and dignity that every human life deserves at the end of life.

The current approaches to the management of chronic and advanced illness recognizing that in many cases, terminal illness is not a situation that suddenly arises. Rather, people with chronic and degenerative diseases, particularly older people, slide gradually and steadily toward ever-more serious degrees of a disease, which may be complicated by the onset of other, complicating medical conditions. To address this reality, hospice should be not only be preserved from the current reckless reduction in patient's lengths of stay, but patient utilization should be maximized within the original legislative tenants of the Medicare Hospice Benefit, and where possible expanded through private payers and Medicaid.

In regard to advance planning, the portability of these directives would be tremendously helpful. States have different witnessing requirements and other variances that can make difficult for the elderly to have their wishes honored wherever they may

be. Documents such as Five Wishes are the key to open discussions among family members as well as professionals.

There are multiple efforts being made to encourage people to have these discussions with their providers. In order to help educate people about the care options and to dispel the misunderstandings, the hospice community, through NHPCO, has just launched a Moments in Life awareness campaign to help educate the public of all the care hospices offer that helps patients live the best life possible. The coalition surrounding National Health Care Decisions Day is working to coordinate a group of diverse organizations toward education and resources on advance care planning. Caring Connections, a project of NHPCO, hosts free downloadable advance directive documents for every state and other resources at [caringinfo.org](http://caringinfo.org).

A national effort to increase hospice utilization during the last two years of life is needed, rather than the current misguided efforts focused on reducing length of stay. Over two-thirds of the patients discharged because decline cannot be documented at the level being imposed by CMS die within two years often with multiple hospital and emergency room visits. If the discharged patients who died during that time had continued in hospice, the costs for the care would still be reduced and the quality of life would be better for them.